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COMMITTEE ON THE RIGHTS OF THE CHILD

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Held at the Palais des Nations, Geneva,
on Monday, 6 October 1997, at 10 a.m.

Chairperson: Miss MASON

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GENERAL DISCUSSION ON THE RIGHTS OF CHILDREN WITH DISABILITIES

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The meeting was called to order at 10 a.m.

GENERAL DISCUSSION ON THE RIGHTS OF CHILDREN WITH DISABILITIES (agenda item 6)

1. The CHAIRPERSON thanked participants for accepting the Committee's invitation. She stressed that the theme of disabled children was invariably raised by the Committee throughout its dialogue with States Parties, from the drafting of general guidelines on the preparation of reports to the adoption of concluding observations. The current discussion would focus on three key aspects of article 23 of the Convention: firstly, the right to life, survival and development (sub-theme I), secondly, the self-representation and full participation of disabled children (sub-theme II) and, thirdly, the right to inclusive education. She invited Ms. Mboi to introduce the theme of the general discussion.

2. Ms. MBOI recalled that there were 500 million people with disabilities in the world, including 140 million children, the majority of whom lived in developing countries, where only 1 per cent had access to support and rehabilitation services and 2 per cent to an education system. Moreover, those children's chances of survival were slim. In some countries, 90 per cent of disabled children did not survive past the age of 20. Furthermore, disabled children were often kept hidden and thus failed to enjoy rights considered to be universal and irrevocable for the rest of society. All participants were thus urged to make a commitment to the world's disabled children by giving a face to the invisible and a voice to the unheard, so that they might be allowed, in accordance with article 23 of the Convention, to enjoy a full and decent life, in conditions which ensured dignity, promoted self-reliance and facilitated their active participation in the community.

3. In that respect, it should not be forgotten that the child, as stated in the preamble to the Declaration on the Rights of the Child, "by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth". Factors endangering the unborn child should therefore also be addressed, such as violence against women, sexually transmitted diseases, drug addiction, tobacco consumption, poverty and inadequate perinatal care, to name but a few. When children were born with a disability, it should be ensured that they were accorded their rightful place in the family.

4. Other conditions hampered the physical, social or psychological development of millions of children, notably armed conflicts and politically motivated violence, but also malnutrition, lack of care, pollution, exploitation and domestic violence. The causes were all well known and, for the most part, avoidable. A double objective should therefore be pursued: firstly, protecting children against becoming disabled and, secondly, ensuring that those children who were disabled were treated fairly and compassionately. In that regard, it should be stressed that the rights of disabled children were by no means confined to article 23 of the Convention; those were special rights spelled out in order to enable disabled children to enjoy the rights accorded by the Convention to all children, particularly the right to the highest attainable standard of health and access to facilities for treatment of illness and rehabilitation of health (article 24), the right to a standard

of living adequate for the child's development (article 27), the right to education (article 28), as well as the right to recreation and culture (article 31).

5. Although numerous countries had ratified the Convention, they did not always live up to their obligations in terms of the measures they implemented in aid of disabled children. By virtue of their varied experience with the problem, participants at the meeting could each be said to hold a piece of the jigsaw puzzle. The time had come to bring those pieces together, in order to identify and interpret those articles of the Convention which particularly applied to the rights of disabled children and to protection against disability, both before and after birth, as well as to develop practical guidance for Governments on strategies and policies for strengthening and accelerating the comprehensive fulfilment of those rights, and to construct a set of indicators for measuring progress towards the fulfilment of those rights.

6. The Committee was determined to do all it could to encourage Governments to prioritize the rights of children with disabilities and, in line with article 12 of the Convention, to ensure that disabled children participated in devising solutions to their problems.

7. Mr. LINDQVIST (Special Rapporteur of the Commission for Social Development on Disability) said that he was responsible for monitoring the implementation of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, a twofold task which involved promoting implementation of the Rules and monitoring the extent to which they were applied. Over the course of his mandate, he had noted that disabled children were often forgotten in development policies, and even excluded, since Governments had no clear understanding of how they might become involved. He was appreciative of the fact that the Commission for Social Development on Disability had recently requested him to study avenues for cooperation with the Committee. In that connection, he now proposed to make a brief comparison between the Standard Rules on the Equalization of Opportunities for the Disabled and the Convention on the Rights of the Child, and then to make a few suggestions on possible areas for joint work.

8. The Convention and the Rules were both inspired by the same goal, namely the fulfilment of human rights through participation, but the Convention derived its impact from the principles on which it was based, whereas the Rules were intended, rather, to give guidance on measures to be implemented for improving the situation. Therefore, there were good grounds for combining the two complementary instruments, especially since the international community's efforts to promote participation of disabled children should also be pursuing a double objective, making the individual more independent and making society more accessible, in the broader sense.

9. Suggesting a number of possible starting-points for cooperation with the Committee on the Rights of the Child, he said that: (1) he would be willing to provide the secretariat with a list of all the reports he had produced on implementation of the Rules during the first part of his mandate (1993-1997); (2) with a view to clarifying the current situation and determining action to be taken, the Committee could cooperate in the collation of information on

disabled children from the country reports; (3) large-scale joint surveys could be conducted on those legislative provisions which prevented disabled children from enjoying their rights; (4) aware that the glaring omission of the situation of disabled children from certain technical assistance programmes was tantamount to discrimination, he was determined to coordinate his activities with those of other United Nations bodies operating in the same domain; (5) a joint mechanism for sharing good practice between countries should be introduced; and (6) the Panel of Experts consisting of representatives of the major non-governmental organizations (NGOs) active in the disability field should also be involved in the above activities, given that they currently had a consultative role in the system for monitoring implementation of the Rules and that, thanks to their extensive networks in more than 160 countries, they could enhance the impact of actions for the disabled. Finally, he urged the Committee to support his efforts to ensure that disabled children were included on the agenda of the International Youth Forum to be organized by the United Nations in 1998 in Portugal.

10. Mrs. STOIKOV (International Labour Organization (ILO)) stressed the need to tackle the root causes of the problem, a principal example of which was child labour, with all its irreversible psychological and physical consequences. With a view to combating harmful practices in that domain, ILO was currently drafting a new convention to include a monitoring system for prohibiting extreme forms of child labour. Moreover, in far too many countries, disabled children were still being excluded from society, against a background of general indifference. The public, especially parents, should thus be made more aware of the need to integrate such children into the community. Finally, it should be remembered that disabled children, if they survived, grew up to become disabled adults, with all the socio-economic costs that implied for Governments. ILO was thus campaigning for inclusion of disabled people in employment, by organizing training programmes tailored to their needs.

11. Mrs. OGUN-BASSANI (United Nations Children's Fund (UNICEF)) said that UNICEF activities in the disabled field focused on young people from 12 to 18 years, a group particularly vulnerable both to prejudice and to sexual, physical and psychological abuse, and whose social, economic and educational needs were frequently neglected.

12. The prime causes of disability were preventable diseases, malnutrition, accidents, assaults during armed conflict, and the explosion of landmines. Necessary measures for rendering assistance to the millions of disabled people included: prevention and early screening for disabilities; early intervention and rehabilitation within the community; capacity-building and resource mobilization; situation analysis and the compilation of statistics required for programme planning and implementation; education and vocational training for disabled children; public awareness-raising; the drafting of legislation in harmony with the Convention or the revision of existing legislation; and the strengthening of cooperation between Governments, United Nations bodies, NGOs and civil society. To that end, UNICEF was contributing to the development and implementation of policies and providing support to countries which had programmes for community rehabilitation of disabled people. It was

also helping to promote capacity- and cooperation-building, and, in some countries, was implementing awareness-raising programmes on the dangers of landmines, including follow-up activities.

13. Mr. PUPULIN (World Health Organization (WHO)) said that WHO activities in the field of disability sought to discourage institutionalization and promote community care, as well as to enable early screening in order to ensure as timely an intervention as possible, so that disabilities were not aggravated through lack of treatment. To that end, WHO was attempting to facilitate the establishment of workshops for the production and repair of artificial limbs in rural areas, since such services currently tended to be located in large towns. Furthermore, studies and research had been conducted to identify local community care options for disabled children. WHO was also assisting countries with policy development, and would be organizing five international conferences in 1997, which would mainly be devoted to the problems of disabled children. WHO was also keen to work with UNICEF in the area of early screening for disabilities, and had already collaborated in other fields with ILO and UNESCO. WHO also looked forward to cooperating with interested NGOs.

14. Mrs. KIELLAND (World Bank) said that not only was it inhuman to neglect the needs of disabled children, but also hugely wasteful of potentially productive human resources. Those infant development programmes which received the support of the World Bank were thus mainly focused on the prevention of diseases capable of causing later disabilities. With the support of the Norwegian Government, the World Bank would also be initiating a research project to study the link between child labour and disabilities, as well as possibilities of early intervention to guard against disabilities.

15. Mr. OVSIOUK (Office of the High Commissioner for Human Rights) said that United Nations human rights bodies and committees had implemented a certain number of measures in the interests of disabled persons, such as the nomination by the Sub-Commission on Prevention of Discrimination and Protection of Minorities of a Special Rapporteur to study the causal link between disability and violations of human rights. The Special Rapporteur had produced a report containing a survey analysis of the provisions of the various instruments adopted by the United Nations and regional organizations, including the Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care. The value of those instruments and of other declarations relating to the promotion and protection of the rights of disabled persons would, however, be judged by the extent to which their provisions were implemented. In that connection, the Office of the High Commissioner for Human Rights was willing to provide advisory services to countries wishing to draft new legislation or to harmonize existing legislation with those standards and principles.

16. United Nations human rights bodies had repeatedly appealed to States to become parties to human rights instruments, particularly to those containing provisions concerning persons with disabilities. In its General Comment 5 of 1994, the Committee on Economic, Social and Cultural Rights had explicitly emphasized the obligation of States parties to the Covenant to foster the progressive fulfilment of the relevant rights of persons with disabilities.

17. The Office of the High Commissioner was also endeavouring to cooperate with intergovernmental and non-governmental organizations in the disability field, with a focus on issues relating to the implementation of relevant international instruments and to the protection of the rights of persons with disabilities.

18. Mrs. WATCHIRS (Joint United Nations Programme on AIDS (UNAIDS)) said that UNAIDS included in the disabled category children with AIDS, HIV positive children and children with parents who had died from AIDS. There were currently one million children in the world with HIV-AIDS. Large discrepancies existed between the developed and developing world, since 90 per cent of the world's disabled children lived in developing countries; in Europe, 80 per cent of infected children reached their third birthday compared to only 50 per cent in some African countries. Those discrepancies were due, inter alia, to inequality of access to medicines. Moreover, child AIDS victims also suffered serious discrimination, many being rejected by their families, or even abandoned. The rights of disabled children enshrined in the Convention were therefore frequently violated.

19. In the field of prevention, UNAIDS was attempting to foster respect for the right to information on measures for avoiding HIV contamination. Children were being involved in the implementation of prevention and health care programmes concerning them. Those programmes mainly targeted vulnerable groups, such as victims of commercial sexual exploitation, refugee and displaced children, children belonging to indigenous minorities, and young girls. The theme of that year's annual UNAIDS campaign against AIDS was "Children living in a world with AIDS".

The meeting was suspended at 11.30 a.m. and resumed at 11.40 a.m.

20. The CHAIRPERSON invited Mrs. Hurst of Disabled People's International to introduce sub-theme I on the right to life, survival and development.

21. Mrs. HURST (Disabled People's International) said that the issue of disabled people should be considered in the first place in terms of human rights. Organizations of disabled people like her own were attempting to convey that message to the media, to the United Nations and all parties concerned, but it had to be admitted that the message was permeating with difficulty, and the campaign begun some 20 years previously was still having to be pursued. The fact that there had been insufficient progress was due to a failure to address the root cause of the oppression of disabled people and of the discrimination and negative attitudes with which they were confronted - which was the denial of their very right to life. In many countries, for example, abortion was suggested for all expectant mothers who risked giving birth to a disabled child. Subsequently, it was the disabled child's right to survival which was violated, since disabled children were all too often neglected, and even refused food in extreme cases. If disabled children did manage to survive, they often ended up being institutionalized or rejected and isolated, sometimes even within their own family, with extreme cases of confinement of the kind regularly reported in the press. There was still a relative paucity of data on such cases. Nevertheless, any value judgement on the quality of life of disabled persons which led to their being denied the right to life, or to survival, constituted a form of eugenics. In that

connection, there had been much talk in the European press recently of the issue of forced sterilization practices, a phenomenon which was actually quite ancient.

22. The London office of Disabled People's International, where she worked, had several people with disabilities on its staff. One of the women, with cystic fibrosis, had two children. Her son attended school normally, whereas her daughter Alice, who would have been four years old that day, had died the previous spring. However, during her lifetime, the little girl had been happy and had also been a source of great joy to her family and friends. The same could be said of many disabled children in the world. It was to be hoped that one day, the birth of a disabled child would be greeted with as much joy as the birth of a child without disabilities.

23. Mr. EIGNER (Inclusion International) said that Inclusion International was an umbrella organization for 173 organizations from 109 countries with the aim of preventing discrimination, violence and neglect of mentally handicapped people. The organization sought to ensure that a mentally handicapped person was not merely viewed as a medical problem and thus focused its activities on social integration and on defending the rights of mentally handicapped persons, particularly their right to life and to survival - both before and after birth.

24. Three key elements should be emphasized. Firstly, in relation to progress in the field of antenatal diagnostics, ever since it had become possible to detect chromosomal abnormalities, abortions had been carried out with the support of the medical profession which constituted a pure and simple denial of the children's right to life, and clear discrimination on the grounds of disability. Children with Down's syndrome were the most at risk. The father of a deceased Down's child, the speaker stressed that by eliminating Down's children, one eliminated some of the most endearing of human beings. The second element to be stressed was that disabled children were also at risk following birth; all too often, a newborn or young disabled child was not given the medical or other treatment accorded to a child without disabilities. Furthermore, it was common amongst today's intellectuals and scientists to wish to restrict the life of severely disabled children, or to limit their treatments. Inclusion International strongly condemned such attitudes, as well as the highly dubious criteria used to define what the quality of life should be. In an attempt to justify deliberately withholding care and food from severely disabled children, it was sometimes claimed that life was not worth living with a severe disability, that financial and medical resources were limited and that the sufferings of the disabled person, as well as those of his or her family, should be avoided, and that a child had just as much of a right to die as to suffer. As a consequence, some courts in their rulings had even taken more account of the so-called sufferings of the child and his or her family - using very dubious criteria - than of the disabled children's right to life. Inclusion International also strongly condemned such Court decisions, as well as the stances adopted by the scientists and intellectuals supporting them.

25. The third element to be stressed related to the fact that disabled children were currently at risk as a result of progress in genetics. Indeed, for many scientists, genetic "defects" were more important than the disabled

child as a person, and it was feared that expenditure on eliminating disabilities would exceed assistance for families of disabled children. The biotechnological debate raised the issue of what actually constituted the "norm", and what constituted a genetic "defect". Modern societies seemed to be seeking to obtain ever more perfect people, at the expense of human diversity - an approach which could only exacerbate the social stigmatization of disabled people. Moreover, it was hard to draw a line between genetic therapy and eugenics; the ability to manipulate the genetic code was a highly dangerous tool. In that connection, it should be mentioned that the UNESCO International Bioethics Committee was working on a draft universal declaration on the human genome and the rights of the human being. Since the declaration at its current stage of drafting did not take into account the above-mentioned concerns, all NGOs campaigning for the recognition of the rights of disabled children were urged to make their voices heard.

26. Mr. FULCI endorsed the views of the previous speakers. He wished to raise the issue of children disabled as a result of landmines and unexploded munitions. He recalled that children in at least 68 countries were currently at risk from more than 110 million landmines, not to mention the millions of unexploded munitions. It was estimated that mines killed and maimed between 8,000 and 10,000 children each year, and impaired the development of millions more. The African continent was the most affected. Children were, of course, particularly at risk from mines since they were naturally curious, and many explosives resembled toys. Nor was the problem of unexploded munitions new; the Nazis, for instance, had left thousands in their wake following the Second World War.

27. It was to be hoped that a maximum number of Governments would sign and ratify the Convention on Prohibition of the Production, Use, Stockpiling and Transfer of Anti-personnel Mines and on Their Destruction, adopted in Oslo on 18 September 1997. In the reports submitted to the Committee on the Rights of the Child, Governments should have to report on progress in the ratification of the Oslo Convention, as well as on measures they were implementing to assist children threatened or injured by landmines. Moreover, mine clearance should be written into all the peace agreements, and countries and societies profiting from the sale of mines should be urged to cease their activities in that domain, and to allocate funds for mine clearance activities. Furthermore, international research on the psychosocial impact of landmine injuries on children should be encouraged. Specific programmes should also be implemented by UNICEF, WHO and other specialized agencies of the United Nations to assist children with mine-derived disabilities.

28. Mr. FOX (American Bar Association) said that it was to be regretted that his country, the United States, had not signed the Convention on the Prohibition of Anti-personnel Mines. A committee of the American Bar Association would be drafting a report which he would forward to the Department of State with a view to advancing the American position. Moreover, he had discovered that the draft Statute for an International Criminal Court contained no reference to the criminal responsibility of children, as if children were never implicated in war crimes or genocides. Nor was that highly delicate issue covered by the Convention on the Rights of the Child or any other international instrument. The reason existing or future United Nations bodies, such as the proposed International Criminal Court, did

not consider themselves to be concerned by such an issue was that they were not bound by international human rights instruments. That issue had come to the fore when the question was posed of whether the Security Council was bound by international human rights conventions, for instance when it decided to impose sanctions on countries such as Iraq, with tragic consequences on the situation of children. Given that the answer currently still seemed to be negative, the Committee on the Rights of the Child should reflect on that issue of concern.

29. When one spoke of disability, one problem was how to define the term. The question had arisen recently in the United States of America when a new law on social welfare had restricted the definition of disabilities, thereby depriving hundreds of thousands of disabled children of welfare assistance. The American Bar Association had helped those children free of charge to appeal against the restrictive measures being imposed upon them; in 70 per cent of appeals, the rulings had been in the children's favour, meaning that more than two thirds of the disabled children had regained access to federal aid. Finally, he agreed with Mr. Fox that during its examination of States parties' reports, the Committee should ask countries what measures they were implementing to make members of the judiciary more aware of the situation of disabled children, especially in cases where the latter were victims of sexual violence and in particular need of advice and defence.

30. Mrs. CLARHÂLL (International Save the Children Alliance) said that over and beyond the right to life, all the rights which disabled children should be able to exercise for the purposes of self-realization should be protected. To that end, studies should be carried out to determine the exact occurrence of generally negative attitudes and behaviour towards disabled persons, so frequently observed. In that connection, available studies confirmed that mentally disabled children were the most prone to sexual abuse, and had much greater difficulty describing how they were treated. When they appeared before the Committee, State parties should adopt a holistic approach to the situation of disabled children, rather than limit their activities to a health and welfare context.

31. Mrs. BLOM (Swedish Organization of Handicapped International Aid Foundation) said that the foundation she represented brought together 14 associations of disabled organizations. Those organizations were characterized by the fact that disabled persons themselves rendered assistance to other disabled persons in developing countries, through various projects. That year, the Swedish-based organization had embarked on several projects devoted to children and their families. Having described her own childhood as a disabled person, she said that upon entering adulthood, she had succeeded in working as a paediatric nurse. Currently, in Sweden, disabled children had the right to live with their families. That right, enshrined in the Convention on the Rights of the Child, was not, however, ubiquitously accorded to disabled children. There had to be a change in social attitudes towards such children in order to enable them to become more integrated in community life.

32. Mrs. KARP remarked that the Committee examined the question of disabled children not merely in the framework of health and welfare, but also in a more general context of non-discrimination and education. At the concluding

observations stage, the Committee should, however, consider the issue from a wider perspective, in order to heighten the awareness of Governments and encourage them to approach the issue more holistically.

33. Mr. WAHLSTRÖM (Inclusion International - Panel of Experts on the Rules of the United Nations) said that the Panel on which he served comprised members of the six major NGOs active in the disability field (Inclusion International, Disabled People's International, the World Federation of the Deaf, the World Blind Union, the World Federation of Psychiatric Users and Rehabilitation International). The Group also provided advice to the Special Rapporteur of the Commission for Social Development on Disability, and campaigned for the respect of human rights in the 160 countries in which it was represented. He recommended that the Committee should cooperate more closely with his group, which already worked alongside several international organizations. He urged the World Bank, in particular, never to ignore disabled persons. It was more important to agree upon concrete actions than to become lost in fine words.

34. Mrs. GUST (Psychiatrist) drew attention to the needs of those who cared for disabled persons (such as parents, heads of educational institutions and trained staff). In many counties, it was mainly mothers who looked after their disabled children and who were thus in need of assistance. It was therefore vital for them to participate in the planning of services for children, and for better training to be provided.

35. Mrs. KIELLAND (World Bank) referred to the case of a friend who had become paralysed as a result of a motor accident, but who had regained hope. The Convention on the Rights of the Child was important not only for children, but also for policy makers and carers. As for the situation of disabled children in developing countries, it was paramount to ensure that disabled people retained a certain self-esteem and found the strength to take up their own defence, in order that they might influence decisions which concerned them, but which were taken by others.

36. Mrs. FRAPPOLA (Inter-American Children's Institute) said that her organization sought to put ideas into practice, as Mr. Wahlström recommended. Working groups, consisting of government members, NGOs and disabled people's organizations, were attempting to define priorities in the social field, taking account of the economic situation in different countries. They also sought to change attitudes towards disabled people, who made up 10 per cent of society. The Inter-American Children's Institute also checked whether legislation contained any discrimination with respect to the disabled, and whether families looking after a disabled child at home benefited from the support they needed.

37. Mrs. WASHEILA SAIT (Disabled Children's Action Group - South Africa) described her experiences as a mother of a disabled child. In South Africa, 90 per cent of mothers of disabled children were unemployed, lived in rural areas and raised their child alone. Their difficult task of ensuring the right of their child to development was rarely taken into account by health professionals. There was a need to establish a partnership between parents

and professionals in that respect. Furthermore, in her opinion the absence of fathers who all too often shied away from their responsibilities was to be deplored.

38. The CHAIRPERSON, having proposed that the Committee examine sub-theme II on self-representation and full participation of the child, invited two teenagers to take the floor on that issue.

39. Miss REX, a 17-year-old South African, related her childhood, in the course of which she had undergone several major operations. She was currently pursuing her education in Cape Town, in a special school for the physically disabled, where she had obtained numerous medals in club athletics. However, she deplored the discrimination against disabled persons in general and appealed to the international community to offer support rather than pity.

40. Miss MAKUTAOME, a young South African who had become deaf in 1976 at the age of two during the anti-apartheid riots, expressed herself in sign language. She stressed the importance of sign language interpreters in hospitals, clinics, libraries and other public places. Thanks to the activities of various NGOs, including the Disabled Children Action Group, young people like herself were managing to lead as normal a life as possible.

The meeting rose at 1.05 p.m.